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CASE STUDY



## Co-designing for mental health: creative methods to engage young people experiencing psychosis

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### ABSTRACT

This paper describes the development and use of creative methods to engage young people experiencing psychosis in co-creation of an online resource to support their education and wellbeing. Engaging young people in a meaningful way, let alone those experiencing psychosis, can be challenging using traditional research methods. Throughout a series of discovery, and prototyping and evaluation workshops, we successfully engaged young people, their families/carers and clinicians in hospital and community mental health settings in enjoyable and empowering co-design activities. These co-design sessions were largely inspired by young people's extensive use of social media metaphors and were adaptable to their interests, preferences and mood. We used storytelling through emojis, a relatable persona with emotion mapping, a card sorting activity and an icebreaker that involved the group co-designing a pizza for our lunch. In the prototyping and evaluation workshops, emotion abstract sketching was used to guide the look-and-feel of the future resource. Using creative methods can enable more than just active engagement of young people with complex health issues. Engagement through creative activities can help draw out the unique experiences and perspectives of potentially vulnerable young people so that solutions that most effectively meet their needs can be explored and developed.

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Co-design; creative methods; youth engagement; user experience; online resources; psychosis

## Introduction

Young people are often reluctant to seek help for mental health problems, and find it difficult to access the health information they need to manage their condition (Gray et al. 2005). However, early support and education from healthcare services is particularly important to improve their long-term prognosis (Rickwood, Deane, and Wilson 2007). Currently, most mental health information is verbally delivered to patients by health professionals, with support from

written materials (Pollock et al. 2004). Patients also search for information independently. However, the information available varies widely in content and quality, is inconsistent and often not patient-centred (Raynor et al. 2007; Pollock et al. 2004).

Young people are highly adept users of online, digital platforms and social media (Lenhart et al. 2010). In Europe, for example, regular Internet use among 16- to 24-year olds has reached 96% (Eurostat 2016), with this age group spending more than 27 hours a week online in the UK alone (Ofcom 2014). However, just under 50% of young people report accessing the Internet to seek health information (Eurostat 2016). Figures are even lower for online mental health information seeking. In a study of views of university students on using the Internet for mental health information and support, only 38% of 18- to 24-year-old students reported to have used the Internet for mental health information (Horgan and Sweeney 2010). However, 68% of them said that, if needed, they would use the Internet to access mental health support.

More recently, the number of studies exploring the potential of the Internet to deliver mental health information to young people has increased. However, the focus of research about online information has primarily been limited to general mental wellbeing (Horgan and Sweeney 2010; Havas et al. 2011; Ellis et al. 2013), and mood disorders such as anxiety and depression (Välimäki et al. 2012; Bradley, Robinson, and Brannen 2012), and how digital platforms could be used to support these conditions. There is still a lack of knowledge on how online and digital platforms can be used to support young people who experience psychosis (Laine, Anttila, and Välimäki 2016). We suggest that this may in part be due to the failure of traditional methodological approaches to engage young people in ways meaningful to them to better understand their experiences and develop solutions that best meet their needs.

This case study describes the challenges involved in developing, designing and employing novel methods and activities to meaningfully engage young people who have experienced psychosis, in the co-creation of an online resource to support their informational and experiential needs and wellbeing.

The project was initiated by healthcare providers involved in early intervention in psychosis services at Auckland District Health Board (Auckland DHB), New Zealand, in need of an electronic, patient-centred resource that could effectively support and guide patient medication education in mental health. The resource was envisaged to be a tool to help facilitate communication between a young person and a clinician, by providing topics that they can discuss together based on the individual's interests and circumstances. The project was led by the Design for Health and Wellbeing (DHW) Lab – a mixed discipline co-design studio located within Auckland City Hospital, New Zealand (Reay et al. 2016; Reay et al. 2017).

## Engaging young people as design partners

In order to communicate credible online health information to youth, it is essential to involve young people as co-creators in the process (Eysenbach 2008). Historically, people with mental health problems have had no power in decision-making on mental health services (World Health Organization 2010). The last few decades have, however, seen a gradual shift in power, moving from one-way, 'provider-centric' models of care to the co-production approach (Bovaird 2007), where service users and their communities are increasingly seen as an essential part of service planning and delivery. Enhancing the empowerment of mental health service users leads to tangible biological, psychological and societal benefits, such as increased emotional wellbeing, independence, motivation to participate and more effective coping strategies (Barry 2009; World Health Organization and Calouste Gulbenkian Foundation 2014).

To become empowered, mental health service users need to be able to have access to information and resources and be included in decision-making (World Health Organization 2010). Consequently, an approach to engage young people in an empowering way should involve actively and collaboratively creating solutions rather than simply seeking passive feedback on their problems or needs.

However, engaging young people in meaningful ways in developing new health resources can be challenging due to their unique culture, behaviours and values (Fitton, Read, and Horton 2013). For young people experiencing psychosis, this can be even more challenging. In their paper on methodological challenges of interviewing teenagers as research participants, Bassett et al. (2008) found that young people often find traditional research methodologies, which are mainly aimed at adults (such as surveys and interviews), boring and intimidating, and those aimed at children patronizing (Bassett et al. 2008). This can lead to apathy, avoidance, silence and discomfort for the participants. Consequently, traditional methods often fail to effectively expose underlying needs, motivations or challenges faced by young end users, and limit their participation in the actual creation of user-centred solutions. It is likely that these issues are amplified if a young person is mentally unwell. Using preset methods such as questionnaires, for example, does not allow for the flexibility that may be needed when working with vulnerable participants with potentially complex behaviours, emotions and needs.

Moreover, these types of methods lack relatable examples to effectively engage younger groups. Methods to encourage youth engagement need to be empowering and enjoyable to encourage the involvement and contribution of young participants (Pedersen and Buur 2000; Mazzone, Read, and Beale 2008). They should relate to situations that are familiar to the participants; be simple, short and based on concrete examples; and have clear outputs and transparency around how participants' contributions will be used (Bowen et al. 2013). These

are particularly important when engaging mental health service users who may be experiencing anxiety and paranoia as part of their condition.

Participatory design or co-design enables users and other stakeholders to participate in the design process to help ensure that solutions best meet their needs (Schuler and Namioka 1993). In this project, we followed Sanders and Stappers' (2008) definition of co-design as a creative process during which both designers and people not trained in design work together in the design development process. This definition aligns well with the activities of the DHW Lab, which aims to draw in those with little or no experience in design (e.g. patients, families and healthcare staff), and provide the tools necessary for them to collaborate and to make meaningful contributions to the design process (Reay et al. 2016).

The involvement of users in the early stages of the design process advances traditional evaluative approaches, where users test already developed prototypes and products (Visser et al. 2005). Making young people equal partners in the decision-making regarding issues that affect them personally is thus vital for designing empowering resources.

## Design process

Following on from consultations with mental health professionals and service user advocacy representatives, a series of four co-design workshops was conducted. These brought together a diverse range of young people who experienced psychosis, their families/support persons, and clinical staff in hospital and community mental health settings. The first two workshops (Discovery workshops) involved a total of 13 participants and were aimed at exploring information needs and preferences for an online resource. In the second round of workshops (Prototyping workshops), the purpose was to generate and evaluate specific solutions for the design of the content and look-and-feel of the new online resource. A total of nine people took part in the second workshop series.

Workshops were co-facilitated by a researcher with a background in health psychology (INK), a User Experience (UX) designer (NH) (both from the DHW Lab) and a mental health pharmacist (CC/AC). Each workshop was approximately two hours long and was audio-recorded. Both rounds of workshops were conducted in two settings: an acute, inpatient setting (the child and adolescent mental health inpatient unit for the Auckland DHB) and a community mental health centre serving the Auckland DHB catchment.

## Workshop activities

Co-creative methods have not been traditionally used with young people experiencing psychosis. Our review of current literature did not identify any studies that employed a truly participatory creative approach to engaging this group of service users. Studies that focused on designing resources for mental illness such as schizophrenia or bipolar disorder relied mostly on interviews to

engage service users (e.g. Valimaki et al. 2008), or sought user feedback only late in the design process (e.g. Matthews et al. 2015). Therefore, our approach was very much experimental and consequently adaptive. Care was taken to develop methods to enable engagement with all participants, regardless of their confidence or physical/mental capacity to verbalize or materialize their thoughts, feelings or perspectives. In preparation for the co-design workshops, the team drew on previous research to identify strategies to create a relaxed and trusting environment for young people, and to enable a productive design process. To keep the atmosphere informal and build rapport, we adopted Zeising and Katterfeld's (2013) advice: we dressed casually, introduced ourselves with first names and arranged seating informally. We made special efforts to emphasize to participants that they were the real experts of their experience, and were guiding us in the co-design of the online resource that would be most valuable to them. In this, they had an opportunity to challenge the current system.

We adopted a flexible approach to the workshop format, showing up with pre-prepared activities, but staying attuned to the changing needs and interests of the participants and adapting to these accordingly (Bowen et al. 2013).

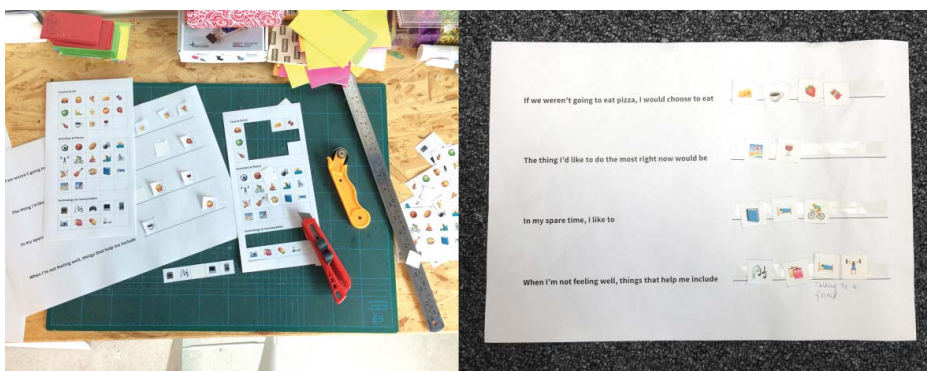
## Discovery workshops

During Discovery workshops, our challenge was to engage young people to share their experiences of psychosis, allowing us to develop an intimate understanding of their needs, fears, concerns and barriers to treatment and management of psychosis, and to explore specific ideas and opportunities for an educational resource. In addition, it was important to understand these same intricacies from the perspectives of family members/support persons.

To achieve this, the methods we developed needed to be appropriate and engaging and related to the types of interactions and experiences familiar to young people. More importantly, each method needed to act as a practical entry point into exploring topics that would help to inform our design solution.

As an icebreaker to our first workshop, we developed an activity based around co-designing a pizza we then ordered for our shared lunch. This activity was an effective and appetizing icebreaker. It also demonstrated to the group how we would work collaboratively throughout the workshops, helping to communicate how each individual's contribution was valued.

As shown in literature, lifestyle factors such as nutrition, exercise, social support, and drug and alcohol use, can contribute both positively or negatively towards people's mental health and their management of psychosis (Samele et al. 2007; Walsh 2011; Connolly and Kelly 2005). To get a glimpse into participants' everyday interests and preferences, and inspired by young people's extensive use of social media metaphors, we developed a simple storytelling exercise using emojis. Participants were given a variety of emoji stickers and a series of incomplete sentences, each relating to a specific lifestyle factor, around



**Figure 1.** Emoji story activity with an example of an emoji story completed by a workshop participant.

which they could build a story (Figure 1). This activity encouraged participants to contribute and share without needing to vocalize their experiences, and prepared the group for the subsequent activity of mapping out areas of interest for the design work.

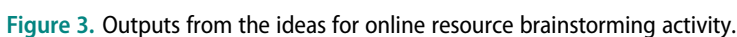
Following this activity, to hear a first-hand account of young persons' experiences relating to psychosis, specifically diagnosis and first-time interactions with clinicians, we presented a relatable persona – a young fictional character called 'Jack' who has just been told by his doctor he has psychosis (Figure 2).

As the group opened up to this activity, they were able to share more intimate concerns, feelings and challenges associated with their condition. By allowing participants to project their thoughts, feelings and experiences onto a fictional character, any sense of direct attention or pressure on a specific individual was dramatically reduced. This proved to be a highly effective and valuable technique to develop insight and understanding into the fears and concerns relating to the diagnosis of psychosis and the first-time interactions with clinicians, for both young mental health service users and their family members/support persons.

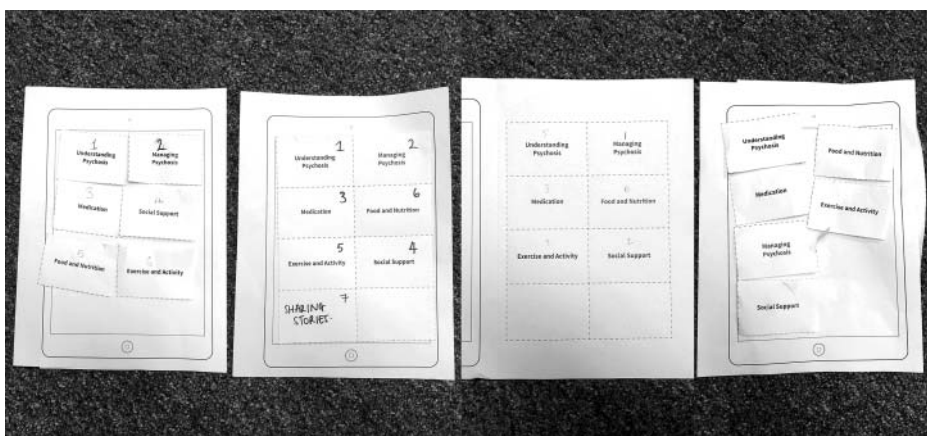
Building on our understanding of people's lived experiences of psychosis, we shifted our attention to focus on how an online resource might support young people and their families' needs. This required a more straightforward brainstorming activity, prompting participants to generate ideas around what the resource could be used for and by whom, the types of information it should provide, the features or functionalities they would like to see, and how it might look and feel (Figure 3). This activity also provided an opportunity to explore how a resource could support the needs of family members and support persons.

During earlier stakeholder workshops, high-level informational topics had been identified as important by the project's advisory team (including mental health clinicians, researchers and service user advocacy representatives). To get a clear sense of the types of information or content young mental health service









**Figure 4.** Examples of completed card sorts for high-level information topics.

users would find most useful, we used a card sorting exercise (Figure 4). Participants could add additional topics on blank cards and include them in the card sort.

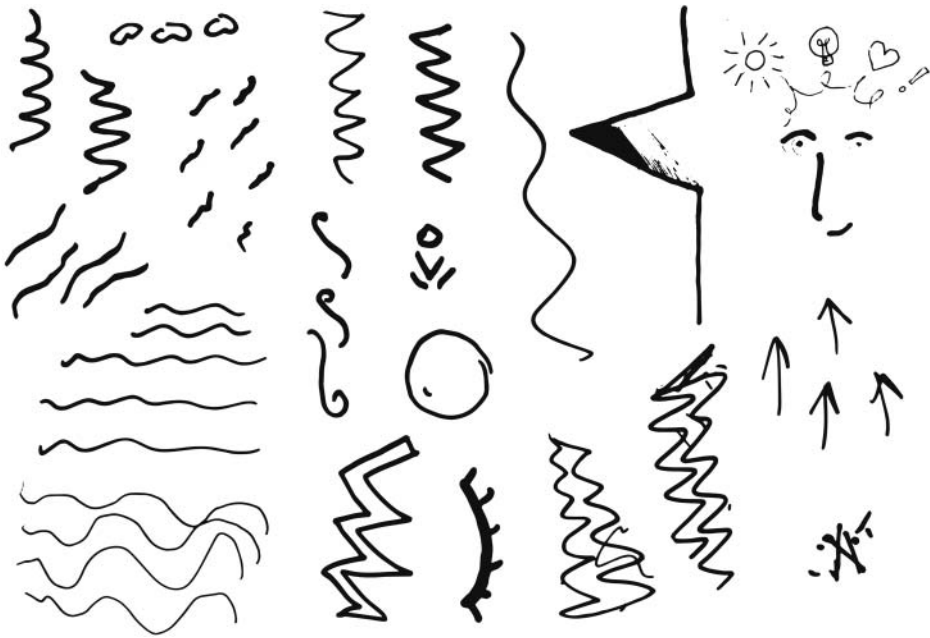
### Prototyping workshops

Co-design by definition implies the involvement of end users throughout the design process, not just the beginning or end (Sanders and Stappers 2008). Rather than limit user involvement to an evaluation of functionality and content, we sought ways to enable service users to contribute to all aspects of the design solution.

As an icebreaker during Prototyping workshops, we ran an abstract sketching activity where participants were asked to draw ‘what a bad day looks or feels like’ and ‘what a good day looks or feels like’ using shapes, patterns or pictures. All participants and facilitators took part in this activity, then shared the ideas behind their sketches. From this activity, two visual themes emerged: bad days were generally represented through sharp, jagged lines or shapes, whilst good days were represented by smooth, wavy or curved shapes. These sketches were not intended to be used directly in the design solution but, rather, used later as inspiration for the visual look-and-feel of the online resource (Figure 5). Drawing enabled participants to express their stories in a creative, visual way, which further strengthened their contribution towards co-designing the website.

Following our Prototyping workshop icebreaker activity, we sought feedback and evaluation of our proposed design solution developed from the previous sessions.

The findings of activities in the Discovery workshops informed the first iteration of the design solution. For example, the users wanted a website, not an app, that would be a one-stop shop for young people and their families to learn more about psychosis and how best to manage it. It needed to use simple, clear



**Figure 5.** Some of ‘abstract emotion’ sketching outputs.

language; take a patient’s perspective and experience; and allow for self-directed learning for those who want it. Consequently, we created a ‘Learn’ section on the website with content tailored to these needs. Participants also expressed the need for a personalised area on the website (that we subsequently labelled ‘Track’) to record medications, side effects and emotions/feelings, that they could use to facilitate conversations with clinicians. Young service users also expressed a strong need for a space to share experiences with others in a similar situation. Thus, we created the ‘Talk’ section, that allows individuals to post and read personal stories.

The intention of the Prototyping workshops was to bring ‘form’ to the initial insights identified by the co-design group, and to use these prototypes as a way to facilitate the unpacking of further understanding. In this instance, more conventional UX testing methods, such as paper prototyping and A/B testing, were used for evaluation and further input. Again, the use of familiar, relevant examples was drawn upon to create an engaging way for participants to provide feedback. In this instance, we used an emoji rating system (Figure 6) and a ‘comments’ section for each page to elicit users’ thoughts and first impressions of the website. These included its clarity of purpose, name, visual presentation, language/wording and tone of voice.

Evaluating the amount/length of content was achieved through a simple A/B test (one page displaying all the content at once, requiring scrolling down the page, another displaying content in smaller ‘chunks’ that could be navigated using the ‘previous’ and ‘next section’ buttons) (Figure 7).

**What is your first impression of the home page?**  
Circle one option  
✓ Stylish icons/design.

**How clear is the purpose of the site?**  
Circle one option  
Great Good It's OK No good It's crap

**What do you think of the name - Talking Minds?**  
Circle one option  
Great Good It's OK No good It's crap

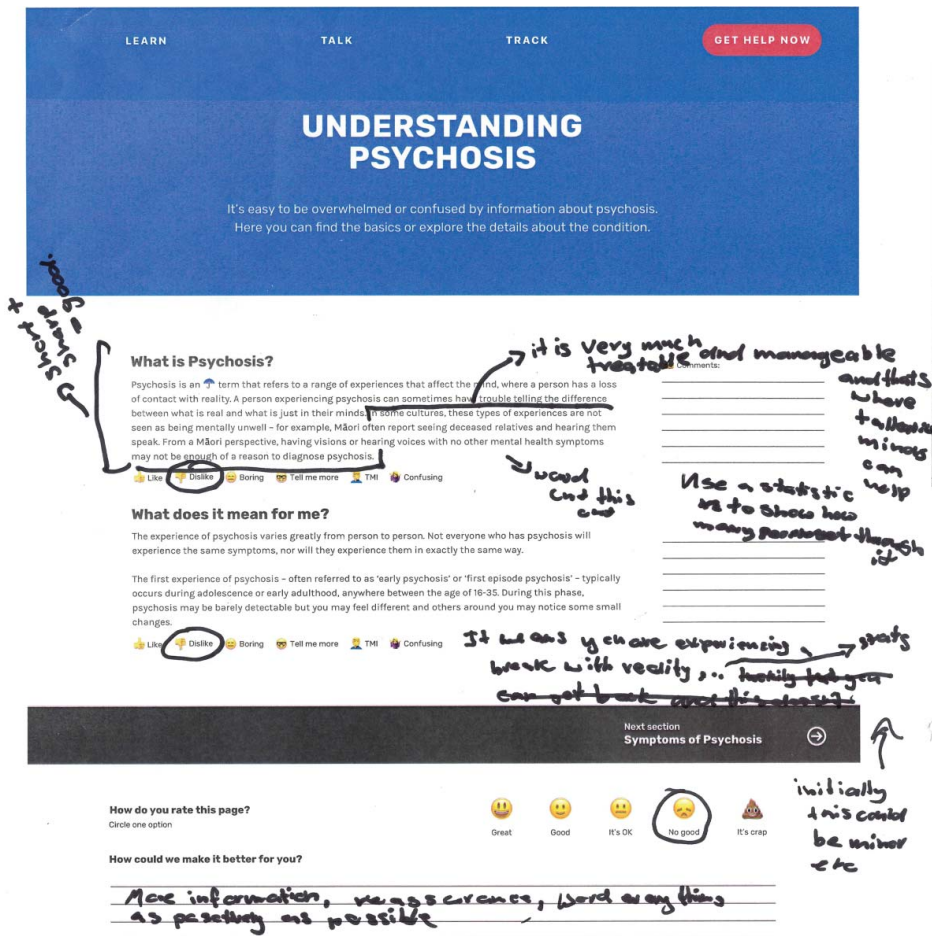
**What other names could we call it?**  
Similar to other website names.

**How could we make this page better for you?**  
On home page - don't add subject headings at top as will all filter down (duplication).  
- Don't like blue/indigo colour.  
- No family content here (should be)

**Figure 6.** An example of feedback on digital and paper versions of the proposed solution for the home page for the website.

We found that most participants preferred to complete this activity in a group assisted by the facilitators, rather than individually. We found this challenging, as it led to multiple discussions within the group making it difficult to take notes and transcribe individual comments from the audio recordings.

Based on user feedback from the Prototyping workshops, the latest iteration of the website incorporated visual elements inspired by the participants' sketches, 'chunked' text on each page rather than scrolling, simplified imagery,




LEARN TALK TRACK GET HELP NOW

## UNDERSTANDING PSYCHOSIS

It's easy to be overwhelmed or confused by information about psychosis. Here you can find the basics or explore the details about the condition.

*100% of people start at this G*

### What is Psychosis?

Psychosis is an  term that refers to a range of experiences that affect the mind, where a person has a loss of contact with reality. A person experiencing psychosis can sometimes have trouble telling the difference between what is real and what is just in their minds. *it is very much treatable and manageable*

*and that's where + follow + mins can help*

*Use a statistic to show how many people get through it*


*wood cut this and*

### What does it mean for me?

The experience of psychosis varies greatly from person to person. Not everyone who has psychosis will experience the same symptoms, nor will they experience them in exactly the same way.

The first experience of psychosis – often referred to as 'early psychosis' or 'first episode psychosis' – typically occurs during adolescence or early adulthood, anywhere between the age of 16-35. During this phase, psychosis may be barely detectable but you may feel different and others around you may notice some small changes.

*It means you are experiencing a break with reality, .. initially but you can get back over this time*

Next section: Symptoms of Psychosis 

How do you rate this page?  
Circle one option

Great Good It's OK **No good** It's crap

How could we make it better for you?

*More information, various sources, word everything as positively as possible*

*initially this could be minor etc*

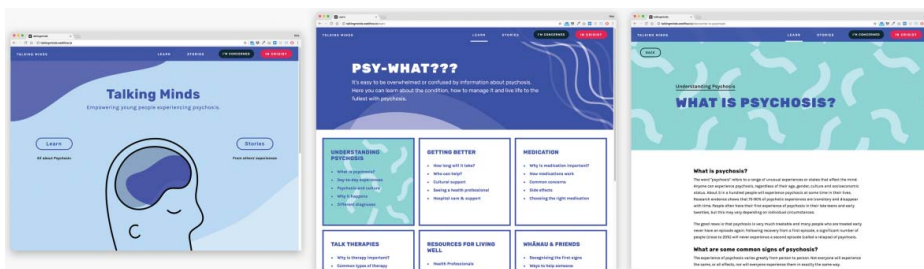
**Figure 7.** A feedback-seeking form on the preferred page navigation – example of a page displaying text in 'chunks'.

text labels and brighter colours. The 'I'm concerned' button was added to the home page to direct users to information on non-urgent support services (Figure 8).

## Discussion

Designing *with*, rather than *for* people faced with mental health challenges where the focus is on solutions, rather than problems, is not common practice. This is despite global recognition that patient and public participation is an important part of best practice in health research (Wolstenholme, Grindell, and Dearden 2017).

This paper demonstrates that young people experiencing psychosis can be meaningfully engaged in co-design using simple, creative participatory methods. Frequent stigma, misrepresentation and bias relating to psychosis



**Figure 8.** Examples of pages in the latest iteration of the website.

(especially as presented online) could have easily led us to believe that the most challenging aspect of engaging with this group would be their state of mental health. However, early in the workshops it was clear that their youth, and associated unique needs and interests, presented a far greater challenge than the fact that they had experienced, or were experiencing severe mental health issues. Adopting a flexible, solution-focused, co-design methodology allowed us to interact with participants in a creative, relatable way, dispelling our misconceptions that people experiencing psychosis would be difficult to engage with. In addition, methods aimed at drawing out participants' creative capacity was an intentional effort towards creating a visual brand direction that starkly contrasted the dark, frightening imagery currently associated with psychosis and related web resources.

Our experience validates the recommendations of previous researchers working with young people with health conditions (Sustar et al. 2013; Välimäki et al. 2008; Bowen et al. 2013). Specifically, it is important to consider young people as equal partners in the design process, by valuing them as experts in their condition and experiences. Incorporating their ideas in concept designs helps to validate their input, resulting in enhanced ongoing engagement. Flexible and adaptive creative activities help to maintain interest, engagement and motivation, especially when mental wellbeing is a factor.

We also found that having open-minded clinician and research partners was critical to the success of the co-design process and is critical for 'design for health' projects to be successful in general. These clinicians were willing to break free from traditional, more passive research methodologies, embrace innovation and contribution of design, and let the future users drive and shape the online resource. Consequently, what was originally intended to be simply a medication education tool grew to become a comprehensive, empowering online resource on psychosis for – and co-designed with – young service users and their support persons.

Of all the co-design activities, we found prototype evaluation the most challenging. This was due to the logistics around recording the input from multiple, simultaneous discussions. In the future, this could be resolved by breaking participants into smaller groups assisted by facilitators to share their feedback at



the end of the activity. Consequently, we would also rethink the value of relying on open-ended written feedback in our future work.

We received positive feedback on our engagement approach from workshop participants, and clinician and service user advocacy stakeholders. Our approach was considered 'different', innovative and novel in the context of mental health care. During workshops, young people gradually opened up to the various activities and became very willing to share their more intimate concerns, feelings and challenges associated with their condition.

Interestingly, once sorted and analysed, the types of information and topics service users identified as most important differed considerably from what clinicians had thought would be most important to their service users. This supports our argument that, without meaningful engagement and contribution from end users and open-minded clinician stakeholders, the development of digital tools to support young people experiencing psychosis may lead to ineffective outcomes.

Our participants attended workshops in their free time, and although we did provide some small material, extrinsic motivators (such as a grocery voucher, snacks and refreshments during workshops), motivation appeared more intrinsic: being endorsed as experts in their condition, sharing their stories, expressing their needs, and working cooperatively to shape a resource to benefit them and others in a similar situation (Bowen et al. 2013). This was supported by repeated attendance, even from participants with physical disabilities affecting their mobility as well as some less vocal participants.

Developing innovative technological solutions with end users to supplement existing, but limited, healthcare resources has the potential to positively impact the recovery and wellbeing of people experiencing psychosis (Välimäki et al. 2008).

The website is now in the final stages of design and testing and is planned to launch by the end of 2017. Young people, their families, and health professionals will continue working together as the resource evolves. We continue to explore future possibilities for the new online resource to grow and incorporate the wide range of capabilities desired by young people experiencing psychosis and their families and support persons. We are currently working with organizations in the field of early intervention psychosis with the aim to adopt the new online resource as part of their operational model.

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## Disclosure statement

Amy Chan has received consultancy fees from Janssen-Cilag, and speaker fees from Novartis, for activities outside this submitted work. She is also a freelance research consultant for Spoonful of Sugar Ltd, a UCL-spin out company specializing in behaviour change. All other authors report no potential conflicts of interest.

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## Notes on contributors

**Ivana Nakarada-Kordic** is a qualitative researcher with a background in human factors and health psychology. Her work at the DHW Lab focuses on user experiences in the healthcare context and how these could be improved through design. As part of the Lab's multidisciplinary team, she is currently involved in various co-design projects involving patients, designers, researchers and clinicians in both hospital and community settings.

**Nick Hayes** is a user experience (UX) designer. His work at the DHW Lab focuses on co-designing digital product experiences for people with mental health conditions, including mild cognitive impairment and psychosis.

**Steve Reay** is co-director of the Design for Health and Wellbeing (DHW) Lab, a collaboration between the Auckland District Health Board and AUT University, initiated to develop an intentional relationship between design process and the area of health and wellbeing, and underpinned by interdisciplinary collaboration and a strong focus on user-centered design.

**Carla Corbet** is an advanced clinical pharmacist in mental health at Auckland City Hospital. She is part of the multidisciplinary team at the Child and Adolescent Mental Health Unit (CFU) in Starship Children's Hospital. She provides a clinical pharmacy service to CFU which involves liaising with other health professionals, patients and their families to contribute to the safe and effective use of medicines.

**Amy Chan** is currently a postdoctoral researcher at the Centre of Behavioural Medicine, University College London. Her research interests focus on optimizing medicines-related behaviour through understanding and exploring the factors that influence human behaviour. Prior to this, whilst this project was conducted, Amy was the clinical pharmacist team leader in mental health at Auckland City Hospital.

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